

Desiree Roge, MD Pediatric Rehabilitation Medicine



Disclosures

• I have no actual or potential conflict of interest in relation to this program.



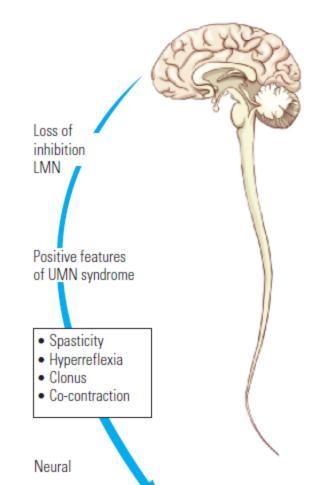
Objectives

- Define the term "spasticity"
- Define the term "dystonia" in comparison to spasticity
- Review non-surgical pharmacologic options for treatment of generalized and focal hypertonia
- Explain how Intrathecal Baclofen (ITB) and Selective Dorsal Rhizotomy (SDR) reduce spasticity
- Describe the patient selection criteria for ITB, SDR and SVDR evaluation of a child who might benefit from an SDR vs Intrathecal Baclofen Therapy vs SVDR
- Explain the surgical approach to an SDR
- Explain the postoperative recovery and rehabilitation care plan after SDR
- Describe the outcomes expected from an SDR and SVDR



Causes of Hypertonicity

- Injury to the brain
 - Cerebral Palsy (CP)
 - Traumatic brain injury
 - Anoxic brain injury
 - Brain malformations
- Spinal cord injury
- Progressive disease impacting CNS
 - Leukodystrophy*
 - Hereditary spastic paraplegia*
 - Multiple Sclerosis (MS) *
 - Other genetic disorders*



Loss of connection to LMN (and other pathways)

> Negative features of UMN syndrome

- Weakness
- Impaired selective motor control
- Poor coordination
- Sensory deficits

Mechanical



Cerebral Palsy

The diagnosis of Cerebral palsy is an umbrella term for a static (i.e. non-progressive) injury to the developing fetal or infant brain resulting in both cognitive and motor impairments





Classification of Cerebral Palsy

Topography (body parts affected)

Type of movement disorder (main type involved)

Functional abilities

Type of Movement Disorder

Motor types

SPASTIC: ~80%

Most common form of CP.

Muscles appear stiff and tight.

Arises from damage to the

Motor Cortex.

ATAXIC: ~1-10% -

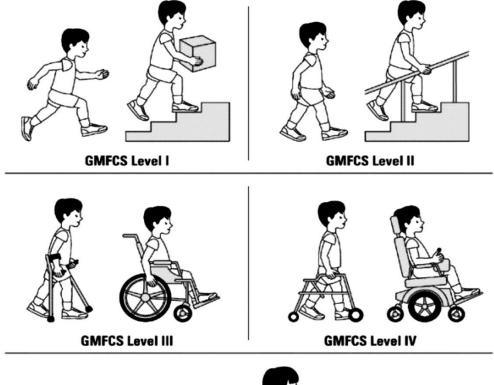
Characterised by shaky movements. Affects balance and sense of positioning in space. Arises from damage to the Cerebellum. **DYSKINETIC:** ~10-20%

Characterised by involuntary movements such as dystonia, athetosis and/or chorea. Arises from damage to the <u>Basal Ganglia</u>.

MIXED TYPES

A number of children with CP will have two motor types present, e.g. spasticity and dystonia.

Gross Motor Function Classification Scale (GMFCS)







What is spasticity?

- Velocity dependent tone
- Disruption of the Upper Motor Neuron (UMN) pathways at cerebral cortex/brainstem/spinal cord
 - "Upper Motor Neuron Syndrome"
- *Spastic cerebral palsy is caused by damage to the motor cortex during critical periods of brain development, in utero or within the first few years of life
 - Infection
 - Stroke
 - Prematurity
- Severity of movement impairments depends on
 - 1. Where the brain is damaged/underdeveloped/impaired and
 - 2. How severe the damage is



What is dystonia?

Sustained/intermittent muscle contractions

 twisting, repetitive patterned movements or abnormal postures

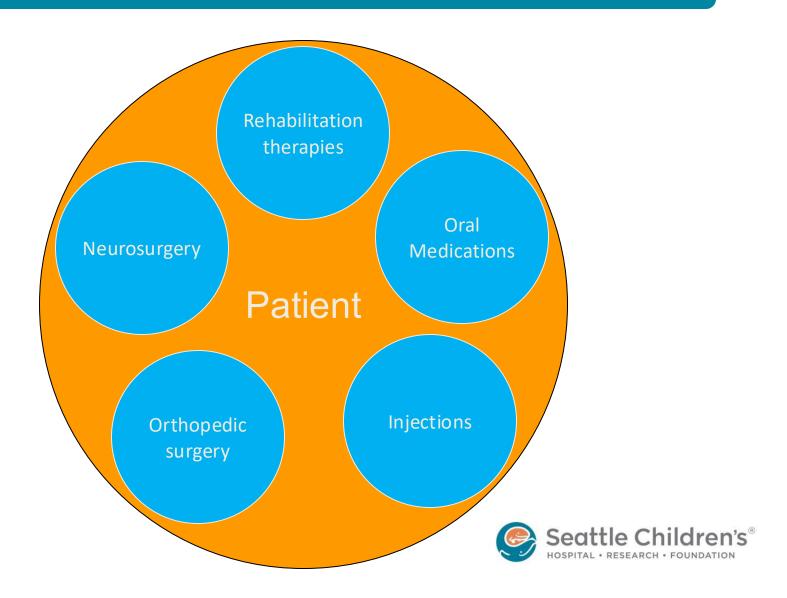
Thought to be due to an interruption of the cortical-basal ganglia-cortical loops

- Neurons in the internal globus pallidus fire slowly and erratically
- Supplementary motor cortex and premotor cortex become excessively stimulated

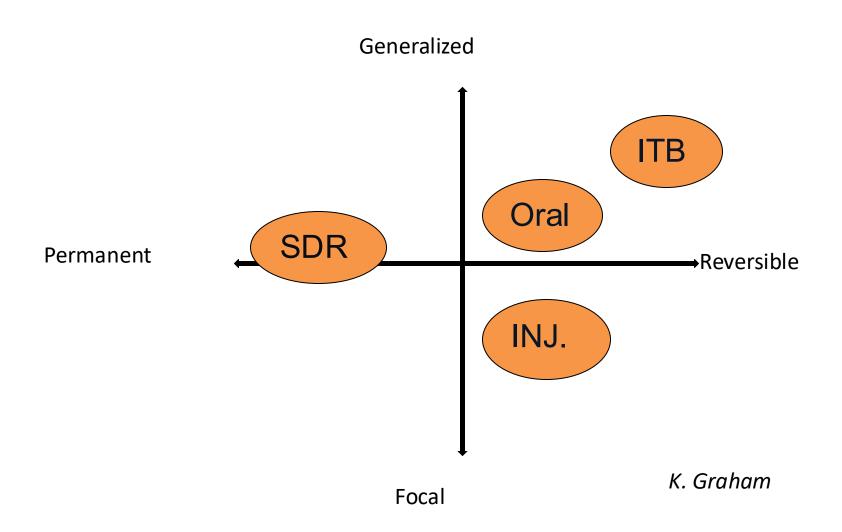




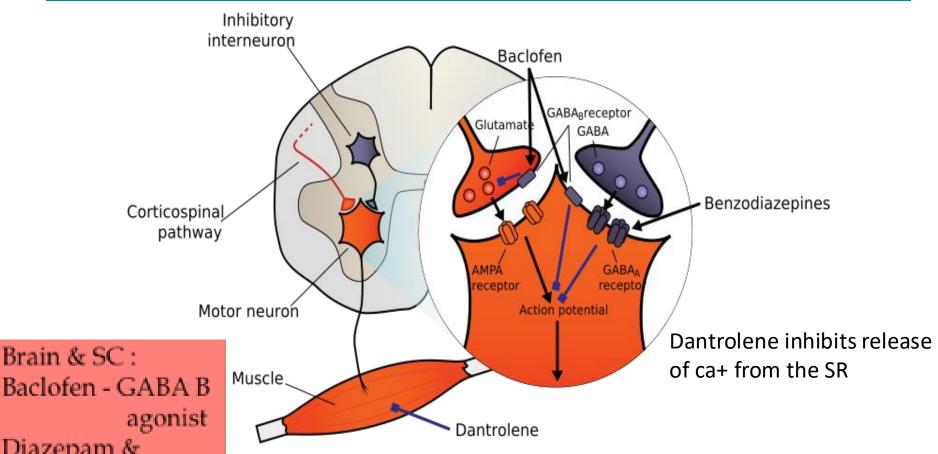
Treatment of Hypertonia



Spasticity Compass



MOA of commonly used oral meds



Diazepam & Clonazepam -GABA A agonist

Tizanidine - Alpha 2 agonist Image from Frontiers in Human Neuroscience 2013

	dose=80mg/day	acute withdrawal: hallucination, seizure, pruritus, severe hypertonia
Diazepam	0.12-0.8mg/kg/day div. q6-8 hrs.	Sedation, CNS & resp. depression, fatigue, weakness, hypotension, hallucinations
Clonazepam	0.01-0.03mg/kg/day div. BID/TID	Sedation, dizziness, ataxia, fatigue, CNS depression, LFT & CBC monitoring if long term use
Tizanidine	0.5-1mg TID, gradually titrate up Max. dose = 6mg/day	Sedation, fatigue, weakness, N/V, loss of appetite, hallucination, hypotension, liver toxicity

Dosing

1-4 y/o: 2.5-5mg BID-TID

5-12 y/o: 2.5-10mg TID Max.

Adverse effects

Sedation, CNS depression, fatigue,

lightheadedness, vertigo, weakness,

hepatotoxic* (check LFT's q6mos.)

malaise, diarrhea, +/- sedation,

weakness, constipation

Medication

Dantrolene Sodium

Baclofen

0.5mg/kg/dose BID, gradually

titrate up to max. of 3mg/kg

From Green LB, Hurvitz EA: Cerebral palsy, Phys Med Rehabil Clin North Am 18:859-882

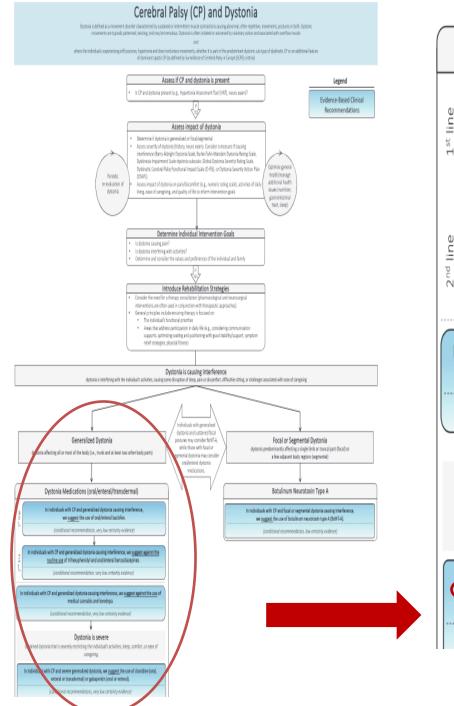
Oral Medications for Dystonia

CLINICAL PRACTICE GUIDELINE



Pharmacological and neurosurgical management of cerebral palsy and dystonia: Clinical practice guideline update

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Darcy Fehlings<sup>1</sup> | Brenda Agnew<sup>2</sup> | Hortensia Gimeno<sup>3</sup> | Adrienne Harvey<sup>4</sup> | Kate Himmelmann<sup>5</sup> | Jean-Pierre Lin<sup>6</sup> | Jonathan W. Mink<sup>7</sup> | Elegast Monbaliu<sup>8</sup> | James Rice<sup>9</sup> | Emma Bohn<sup>1</sup> | Yngve Falck-Ytter<sup>10</sup>
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Dystonia Medications (oral/enteral/transdermal)

In individuals with CP and generalized dystonia causing interference, we suggest the use of oral/enteral baclofen.

(conditional recommendation, very low certainty evidence)

In individuals with CP and generalized dystonia causing interference, we suggest against the routine use of trihexyphenidyl and oral/enteral benzodiazepines.

(conditional recommendation, very low certainty evidence)

In individuals with CP and generalized dystonia causing interference, we <u>suggest against the use</u> of medical cannabis and levodopa.

(conditional recommendation, very low certainty evidence)

Dystonia is severe

sustained dystonia that is severely restricting the individual's activities, sleep, comfort, or ease of caregiving.

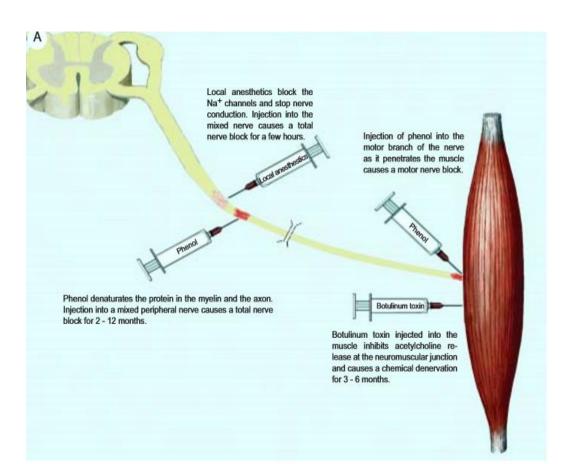
In individuals with CP and severe generalized dystonia, we <u>suggest</u> the use of clonidine (oral, enteral or transdermal) or gabapentin (oral or enteral).

(conditional recommendations, very low certainty evidence)

Focal/Segmental treatment

- Botulinum toxin injections chemodenervation
- Phenol 3-5% or Alcohol chemoneurolysis or selective motor nerve block





Botulinum Toxins

- 8-18 units/kg per event, up to 300 U TBW
- Single event, multi-level injection
- Intervals between injections : at least 12 wks
- May be up to 3-4 times per year
- Systemic adverse events following BoNTA inj,1-2%, and are associated with increasing co-morbidities and dose of botulinum toxin
- In 2009, FDA Black Box warning added: possibility of distant spread of toxin beyond the treatment area, with possibility of breathing, swallowing difficulties and risk of death.
- Local adverse events: pain, bruising at injection sites
- Ultrasound guidance, EMG, E-stim >> anatomic localization
- As an adjunct to other treatment modalities such as physical/occupational therapy, serial casting, orthosis/bracing

Botulinum Toxin



SARCOPENIA, CEREBRAL PALSY, AND BOTULINUM TOXIN TYPE A

Iqbal Multani, HSc, MD

Jamil Manji, MSc, MD

Min Jia Tang, MBBS

Walter Herzog, PhD

Jason J. Howard, BEng, BMedSci,

MD, FRCSC

H. Kerr Graham, MD, FRACS

Abstract

- » Sarcopenia is common in both the elderly and children with cerebral palsy.
- » Children with cerebral palsy have muscles that are much smaller than muscles in typically developing peers.
- » Injections of botulinum toxin type A (BoNT-A) result in acute muscle atrophy in animal models and in human subjects.
- » It is not known when or if muscles recover fully after injection of BoNT-A.
- » These findings have implications for management protocols.

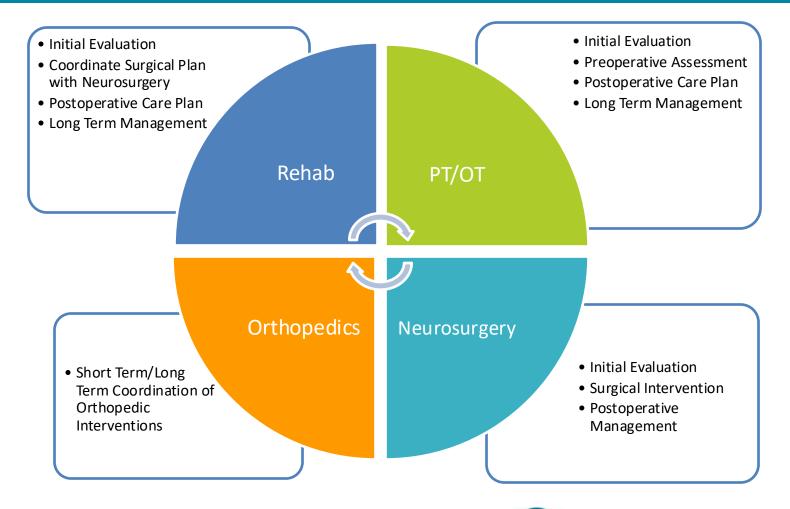
Phenol 3-6% Chemoneurolysis

- Selective motor nerve block : Obturator nerve for hip adductors; Musculocutaneous nerve for elbow flexor, tibial nerve for ankle plantarflexors
- More uncomfortable, burns
- Effect is immediate and longer lasting than Botulinum toxin
- Need electrical stimulation and/or ultrasound guidance, and sedation in children
- Main AE: paresthesia/allodynia

Surgical Tone Management Program

- Intrathecal Baclofen Therapy (ITB)
- Intraventricular Baclofen Therapy (IVB)
- Deep Brain Stimulator * (DBS)
- Selective Dorsal Rhizotomy (SDR)
- Selective Dorsal Ventral Rhizotomy (SVDR)

Comprehensive Evaluation Process





What is a baclofen pump

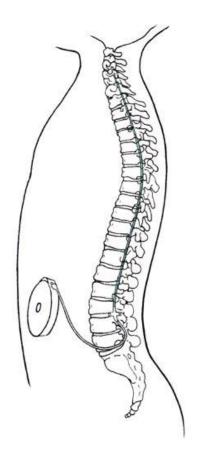
A "baclofen pump" is a fully implantable drug delivery system for administration of baclofen directly to the spinal fluid:

- Pump implanted in the lower quadrant of the abdomen (most commonly on the right)
- Catheter tip in the intrathecal space and tunneled subcutaneously to pump pocket
- Tablet Programmer dose and other pump settings are adjusted noninvasively via telemetry









ITB Patient Selection

- Patient selection is essential to therapeutic success
- Selection criteria:
 - Have spasticity of spinal or cerebral origin that is refractory to oral baclofen or have experienced intolerable side effects at effective doses
 - Sufficient body mass to support pump bulk and weight (Usually >15kg)
 - Social environment conducive to frequent refills (at least every 6 months)
 - Able to reach ITB provider in case of emergency
 - Demonstrate positive response to single bolus dose of intrathecal baclofen via lumbar puncture (baclofen test dose)*

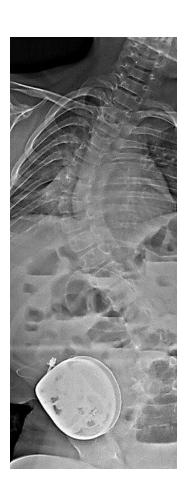


Goal setting & patient selection are key!!!

- Goals
 - Improve functional mobility
 - Improve comfort and ease of caregiving
 - Improve positioning
- Catheter level depends on topography and type of hypertonia
- Will not change fixed musculoskeletal deformities
- May unmask weakness so dose may need to be titrated to allow use of some spasticity

Benefits of ITB

- Lower dose
- Fewer side effects
- Medication titration
- Effective in treating dystonia and spasticity
- Reversible
- Works for legs, trunk, arms, neck, face
- ITB test dose to evaluate response prior to implant



Therapy Maintenance and Risks

- Pump refills
- Pump replacement about every 6+ years
- Risk of pump failure, catheter failure
- Surgical risks
 - Infection
 - Spinal fluid leak
- Baclofen withdrawal
- Baclofen overdose

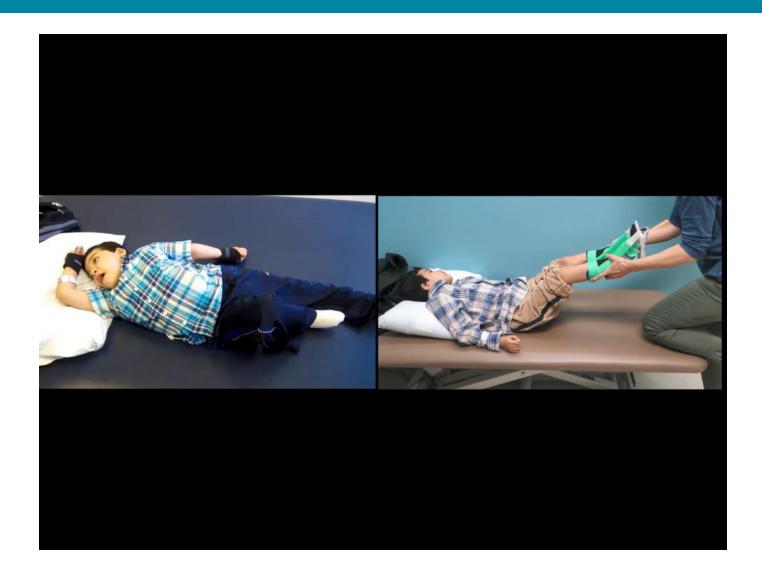


Outcomes of ITB

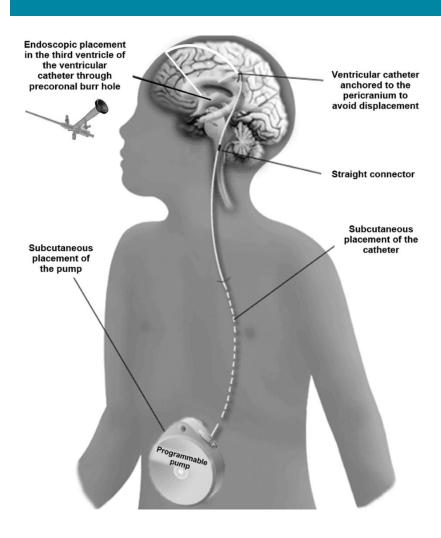
- Functional (GMFCS II, III)
 - Decreases spasticity
 - Improves gait

- Care/Comfort (GMFCS IV, V)
 - 78% decrease in dystonia at rest
 - 48% decrease in dystonia during activity
 - Improvements in self care, communication, sitting and fine motor function

ITB Patient example

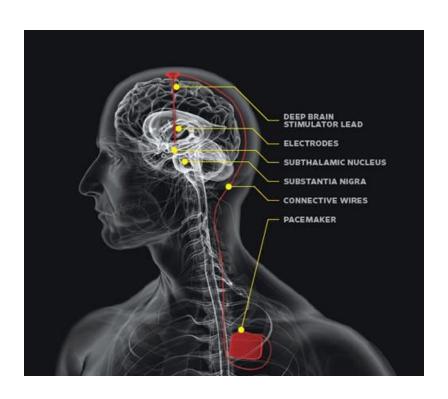


IVB





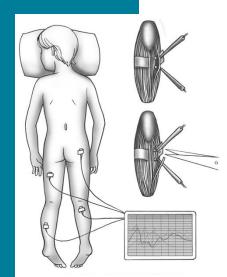
Deep Brain Stimulation



- Primary/genetic dystonias & Parkinsons
- May help motor non motor symptoms
- Applications now include dyskinetic and dystonic CP- ot sufficient evidence
- Outcome of DBS in dystonic CP Variable: 15-50% motor improvement, could be slightly lower and higher depending on the studies.
- Some studies showed that dystonic CP patients may take up to 24 months to observe these benefits.

What is Selective Dorsal Rhizotomy?

Selective Dorsal Rhizotomy is a surgery to expose and cut abnormal sensory spinal nerves that contribute to *spasticity*.



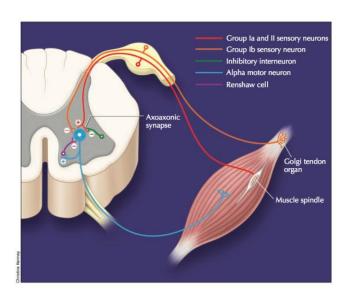
"Selective" refers to the identification of those specific nerves that are both innervating the muscle groups negatively impacting the patient's function and gait and responding abnormally to electrical stimulation.

"Dorsal" (or sensory) refers to the type of nerve being targeted.

"Rhizotomy" refers to the cutting of that nerve.

How SDR Treats Spasticity

- How a stretch reflex works:
 - Sensory input from the muscle
 - Integration of sensory information in the spinal cord
 - Output of information to the muscle
- How spasticity affects this:
 - Loss of inhibition from the brain → overactivity of the muscle
- How SDR affects this:
 - Decreases sensory input into the spinal cord → decreasing abnormal muscle output



SDR Patient Selection Criteria



- Any age (typical age range 3 8 years)
- Diagnosis consistent with CP
- Spasticity predominant movement disorder
- Little to no dystonia
- Good strength and motor control
- ROM adequate
 - May consider combining SDR with orthopedic muscular procedures such as tendon lengthening
- Good potential for rehabilitation
 - Patient/family commitment
 - Access to therapies
- Patient and family/medical team goals in alignment

SDR Evaluation – Examination

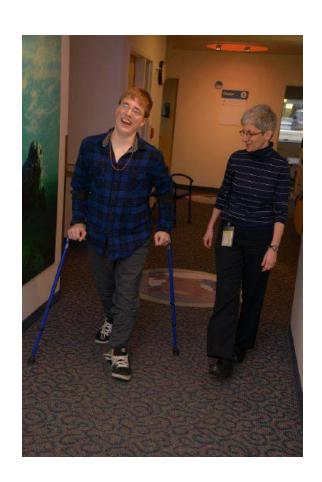
- General
- Musculoskeletal
 - ROM
 - Hips
- Neurological
 - Tone (spasticity vs dystonia)
 - Reflexes
- Neuromuscular
 - Strength





SDR Evaluation - Function

- Gait
- Motor control
- Transitional movements
- Objective information/testing
 - GMFM
 - GMFCS
 - BAD
- Equipment
 - Orthotics





Tone Management Outcome Measures

Body Function & Structures

Range of motion (ROM)

Strength

0

Modified Ashworth/Modified Tardieu (MAS/MTS)

Barry Albright Dystonia Scale (BAD)

Hypertonicity Assessment Tool (HAT)

Selective Control Assessment of Lower Extremities (SCALE)

Selective Control of Upper Extremities Scale (SCUES)

Activity

Gross Motor Function Measure (GMFM)

Functional Mobility Scale (FMS)

Manual Ability Classification System (MACS)

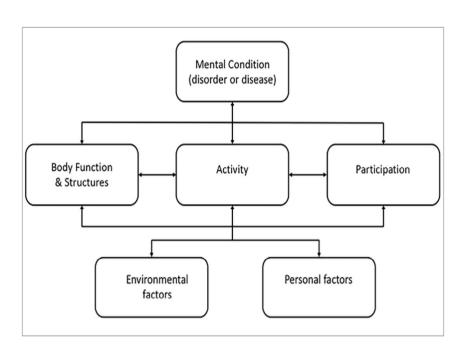
Participation

CP GOAL: Cerebral Palsy Gait Outcomes Assessment List

CPCHILD: Caregivers' Priorities and Child Health Index of Life

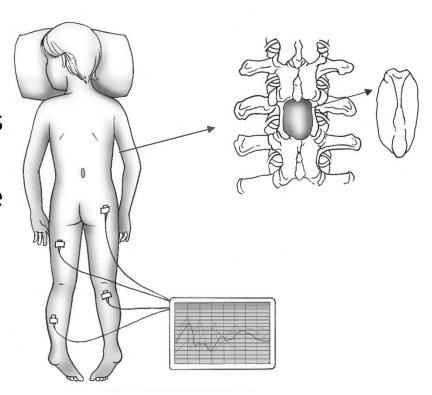
with Disabilities

International Classification of Functioning, Disability, and Health (ICF) Model



SDR – Surgical Approach_{1,2}

- General anesthesia
- Patient in prone position
- Neuro-monitoring team places electrodes
- 1-2 inch incision is made in the lumbar spine
- Single level laminectomy performed

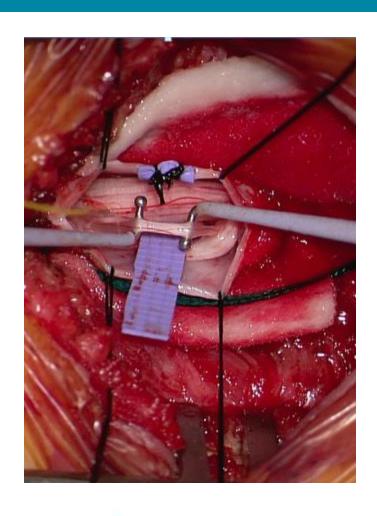


- 1 Bales J, Apkon S, Osorio M, Kinney G, Robison R, A, Hooper E, Browd S, Infra-Conus Single-Level Laminectomy for Selective Dorsal Rhizotomy: Technical Advance. Pediatr Neurosurg 2016;51:284-291
- 2 Park TS, Gaffney PE, Kaufman BA, Molleston MC; Selective Lumbosacral dorsal rhizotomy immediately caudal to the conus medullaris for cerebral palsy spasticity. Neurosurgery 1993;33:929-933



SDR – Surgical Approach (continued)

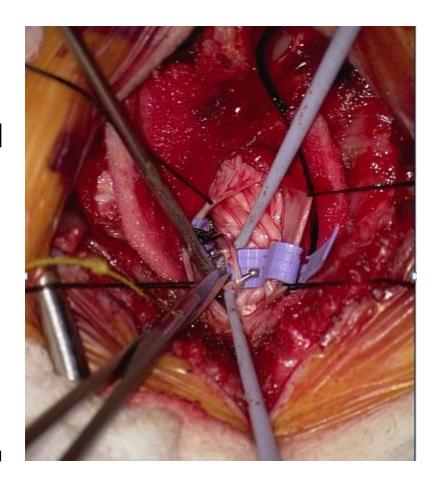
- Dorsal and ventral roots identified
 - Visually and electrically
 - Ventral roots activated at low threshold
 - Segmental level verified
- Ventral roots placed behind a silastic band





SDR – Surgical Approach (continued)

- Dorsal root teased into 3-8 rootlets
 - Rootlets looped and pulled away from CSF for stimulation and monitoring
 - Transection of the aberrant nerve roots



1 Bales J, Apkon S, Osorio M, Kinney G, Robison R, A, Hooper E, Browd S, Infra-Conus Single-Level Laminectomy for Selective Dorsal Rhizotomy: Technical Advance. Pediatr Neurosurg 2016;51:284-291



Intraoperative Monitoring

- Goal
 - Separate the 'normal' from the 'abnormal' by scoring system
 - Section the 'most abnormal' and leave the rest
 - 50-75% rootlets sectioned*





Intraoperative Monitoring (continued)

- Electrode placement –
 subdermal electrodes
 - L1/L2 adductors
 - L2/L3 vastus medialis
 - L4 anterior tibialis
 - L5 gastrocnemius
 - S1 biceps femoris
 - S2/S3 perirectal





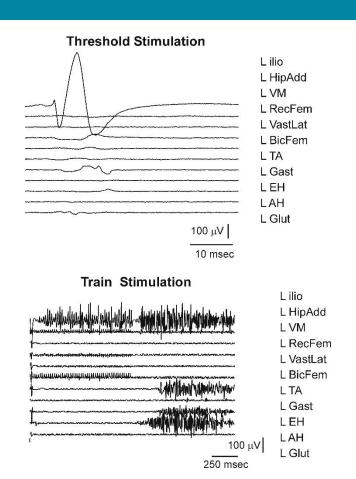
Nerve Root Selection Criteria

Normal response

- Single response to repetitive stimulation
- Multiple response with decremental amplitude pattern

Abnormal response

- Incremental amplitude pattern
- Motor response in non-targeted muscle
- Response is sustained





Rehabilitation after SDR



- NSR Service approximately 3 days
 - Patient lays flat for 72 hours to prevent CSF leak
 - Can log roll
- RHB Service approximately 3 weeks
 - Intensive inpatient rehab program
 - Option for outpatient therapy if patient/family unable to accommodate long term admission (case by case basis)
- Outpatient physical therapy 3-5 times a week for 6-12 months
- Follow up visit with the Surgical Tone Management team at 3, 6, 12, 18 and 24 months
- No evidenced based protocols exist

Outcomes of SDR

- Reduction in spasticity
- Improvement in ROM
- Functional improvement
- May decrease need for orthopedic surgery
- Functional gains maintained
 17-26 years
- Improved gait kinematics



Buizer et al. 2016 Ingale et al. 2016 McLaughlin et al. 2002 O'Brien et al. 2005 Miller et al. 2017 Langerak N, et al. 2012 Novak, I, et al. 2019

SDR Outcomes – 5 and 10 year follow-up

- Spasticity reduction maintained
- Range of motion maintained or improved
- Motor function improvement in GMFM
 - A 7% improvement in GMFM score translates to a median positive change in function, positively impacting participation
 - SCH program average improvement in GMFM is 7%

Mittal S et al. J Neurosurg 2002; August; 97: 3153-25 Nordmark E et al. BMC Pediatrics 2008; 8:54. Josenby AL et al. Dev Med Child Neuro 2012 May;54(5):429-35. GMFM User's Manual, 2nd Ed. 2013:21





SDR – Theoretical Contraindications

- Presence/degree of dystonia
- Type of CP (hemiplegia, quadriplegia)
- Intellectual disability
- Age
- GMFCS levels IV-V
- Poor motor planning and excessive underlying weakness





SDR - Potential Complications

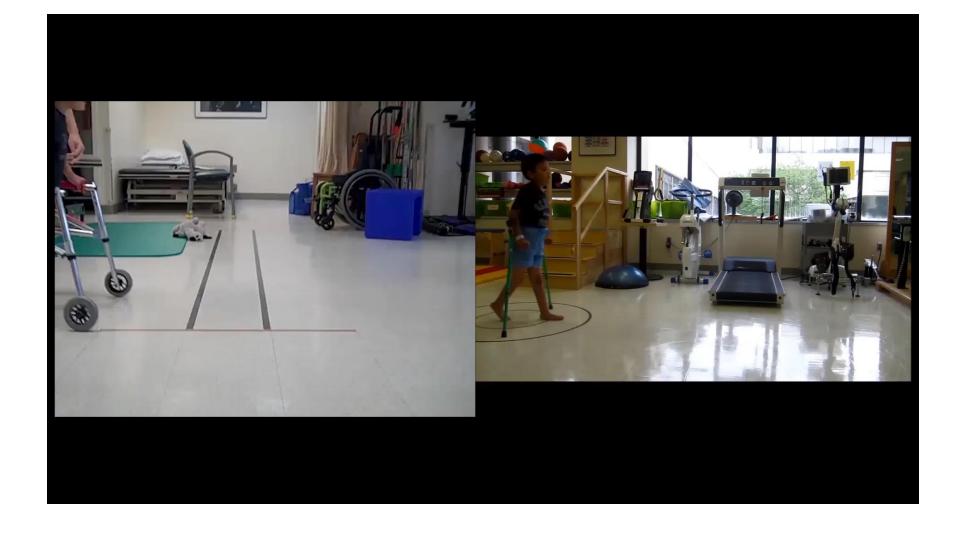
- Infection₁
- Spinal fluid leak
- Rare bladder incontinence
 - Transient urinary retention
- Back pain or other neuropathic pain



Bales J, Apkon S, Osorio M, Kinney G, Robison R, A, Hooper E, Browd S, Infra-Conus Single-Level Laminectomy for Selective Dorsal Rhizotomy: Technical Advance. Pediatr Neurosurg 2016;51:284-291



Patient AB – Before/After SDR



Palliative SDR in Moderate – Severe CP

- Decreased spasticity, improved PROM
- High degree of patient satisfaction
- Potential option for nonambulatory children in certain situations
 - Rural locations
 - No goals or potential for ambulation/weight-bearing

GMFCS level I Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited. GMFCS level II Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or use wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running GMFCS level III Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when travelling long distances and may self-propel for shorter distances. **GMFCS** level IV Children use methods of mobility that require assistance or powered mobility in most settings. Th walk for short distances at home with physical assistar or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility. GMFCS level V Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and

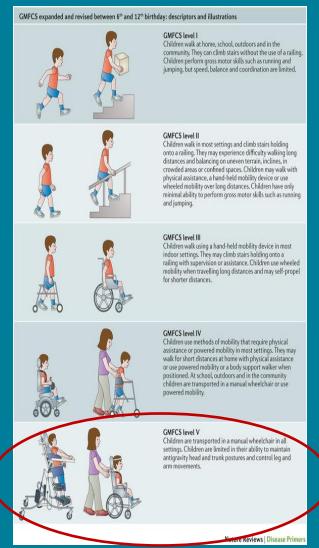
Reviews | Disease Primers

GMFCS expanded and revised between 6th and 12th birthday; descriptors and illustrations

Kan P et al. Childs Nerv Syst. 2008; 24: 239-243.

Selective Dorsal Ventral Rhizotomy (SDVR)

- Done only for palliative goals and for patients with both spasticity AND dystonia
- Both DORSAL AND VENTRAL nerve roots are dissected
- Typically, 90% of ALL VENTRAL nerve roots and 75% of ALL DORSAL nerve roots are cut (per Gillette protocol/anecdotal evidence)
- No RHB provider present at time of surgery due to palliative goals
- Used when ITB not an option but does not preclude insertion of one if necessary
- SDVR offers significantly decreased healthcare costs and resource utilization relative to ITB



Hartman E. 2025

Summary

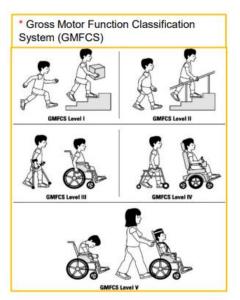
- ITB and SDR are effective interventions in reducing spasticity and improving function
- SDR offers the appropriate patients a single surgery with no device maintenance for primarily spastic patients
- SVDR may be an alternative to decrease dystonia/spasticity in GMFCS 5 patients with strict goals of care and cofort
- ITB is effective in managing upper AND lower extremity spasticity as well as dystonia (secondary)
- Long-term benefits of both interventions
- ITB complications fairly common, SDR complications rare
- Post-operative therapy post SDR in ambulatory patients (GMFCS 1-3) is critical to optimizing functional outcomes



Referral Algorithm: Hypertonia

Does the patient have hypertonia that interferes with mobility, positioning, or cares? YES **GMFCS IV or V** What is the patient's gross motor classification?* **GMFCS I-III** NO Does the patient have goals for Does the patient have ambulation or potential for ambulation YES Has the patient tried care/comfort goals with/without assistive devices? other nonsurgical interventions such as YES NO oral medications, therapy, Botox/phenol YES Not a candidate for Is the patient at least injections? referral to Tone 2 years old? Management NO NO. at this time YES Refer to *Consider referral Refer to Surgical Tone Refer to Rehabilitation to Rehabilitation Rehabilitation Management (STM) Clinic Medicine Medicine for a for Selective Dorsal Rhizotomy Medicine for a general rehab general rehab (SDR) evaluation for a general evaluation evaluation rehab evaluation Refer to Surgical Tone Management (STM) Clinic for Intrathecal Baclofen (ITB) Therapy, Selective Dorsal Rhizotomy

(SDR) or Selective Dorsal Ventral Rhizotomy (SDVR) evaluation



To learn more



Scan QR Code

Refer a patient to the Tone Management Program in Rehab Medicine

Seattlechildrens.org/tone-management



How do I refer a patient for a surgical evaluation with the Tone Management team at Seattle Children's?

CALL (206) 987-5917

EMAIL tone@seattlechildrens.org

ONLINE REFERRAL FROM COMMUNITY PROVIDER

Access referral instructions on <u>www.seattlechildrens.org</u> by searching "refer a patient" and selecting "Rehabilitation Medicine clinic"

To learn more



Seattlechildrens.org/tone-management

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